

# **Improving services for adults with autism in Calderdale**

Presented to the Calderdale Council  
Adult Health and Social Care Scrutiny Panel  
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## 1. Report Summary

This report highlights a range of issues faced by adults in Calderdale who have, or who are seeking, a diagnosis of an autism spectrum condition (ASC).

We outline recent improvements to services, including the commissioning of a diagnostic pathway, and the funding of the Autism Hub which is now in its second year.

Despite these developments Healthwatch Calderdale (HWC) continues to hear regularly from adults with ASC, who are raising the same concerns as before, and whose lives are still being negatively affected by the lack of appropriate services and support.

We explain briefly what ASC is and how it can affect adults lives, including higher rates of suicide and mental health issues than the general population, as well as frequently having a range of co-occurring conditions such as Attention Deficit Hyperactivity Disorder (ADHD), dyslexia, dyspraxia, and epilepsy.

We clarify the benefits for adults who are on the autism spectrum of having a diagnosis, but also the difficulties they may face in trying to get an assessment.

Data included in the report shows that the diagnosis rate for adults with ASC in Calderdale is extremely low, and we believe that the reasons for this need to be explored.

We include a range of recommendations, some of which could be easy to action, such as improved data collection, increased training for professionals, and better understanding and use of reasonable adjustments. Other recommendations may be more challenging, but may be achievable through new ways of working, and better collaboration between services.

We would like to thank all the experts by experience who have spoken to us about the issues they have faced, including members of the Autism Hub in Halifax who have welcomed us to their group and given us their valuable feedback. We would also like to thank members of the Calderdale Autism Strategy Group who have contributed their thoughts, and the Adults with Autism Service for the feedback and information they have given us.

## 2. Introduction

**Healthwatch Calderdale frequently hears from adults with autism spectrum conditions about a range of difficulties they face accessing suitable health and social care services.**

Issues have included, but are not limited to, the following:

- Difficulties accessing a diagnostic assessment
- Long waiting lists for assessment without indications of timescale
- Difficulties accessing a second opinion
- Lack of post-diagnostic services in Calderdale
- Low levels of autism awareness among professionals and in services
- Reasonable adjustments not being understood or put in place
- Lack of access to appropriate mental health care and support
- No general advocacy services available for support
- Very little support for families and carers of adults with autism

**In October 2017 we published our report, ‘Adults experiences of Autism Services in Calderdale and Kirklees’.** We wanted to increase our understanding of the difficulties people were facing, so we collected feedback from adults with autism, and their families and supporters, using online surveys and one-to-one engagement. The report highlighted a range of issues which were negatively impacting on the everyday lives of people with autism.

**Since then there have been some positive changes:**

- a diagnostic pathway for adult ASC was commissioned by Calderdale Clinical Commissioning Group and has been in use since April 2018;
- the CCG also put extra funding into clearing the waiting list down to the NICE 3 month guidelines, and SWFYT has managed to achieve this;
- Calderdale Council funded a one-year pilot for an Autism Hub, which has since been extended for a further two years.

**But we continue to hear from people with autism spectrum conditions, who are still raising similar concerns as before, despite these improvements.**

We have brought this report to the Adult Health and Social Care Scrutiny Panel, to raise the voices and concerns of members of the public, with the aim of driving improvement in services for adults with autism in Calderdale.

### 3. What is autism spectrum condition (ASC), and how does it affect people's lives?

**ASC is a lifelong developmental condition affecting how people perceive the world and interact with others.** Autistic people see, hear and feel the world differently to other people. If you are autistic, you are autistic for life; autism is not an illness or disease and it cannot be 'cured'.

**The term 'autism spectrum' refers to the range of ways the condition presents itself in an individual.** This can vary greatly from person to person and throughout their life. All autistic people share certain difficulties, but being autistic will affect them in different ways. Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support.

**Asperger syndrome is a form of autism, and is generally seen as someone with autism who has an average or above average IQ.** Due to changes in diagnostic criteria Asperger syndrome is no longer used as a diagnostic category, although some medical professionals may still use this term as certain people will have had a historical diagnosis.

### 4. Autism, mental health and co-occurring conditions

**People with autism have a higher rate of mental health issues than the general population.** Autism is not a learning disability, or a mental health problem, however, there are higher rates of mental health difficulties in this community, such as anxiety and depression, when compared to the general population.

**Suicide rates for autistic people are much higher than the general population.** For autistic people without a learning disability, the rates have been found to be nine times those of the wider population (Autistica Report – 'Personal tragedies, public crisis' - 2016).

**Autism is often diagnosed alongside a range of other conditions.** It's important to support people with more than one condition in a way that meets all their needs, while understanding that the needs arising from autism are distinct. Other conditions that affect autistic people include ADHD, dyslexia, and dyspraxia, (NHS: Other conditions that affect autistic people - 2019), while between 20% and 40% of autistic people also have epilepsy, with this rate increasing steadily with age (Autistica Report – 'Personal tragedies, public crisis' - 2016).

## 5. Policy Context

**The Autism Act (2009)** established the requirement for the Government to produce a strategy for meeting the needs of adults in England with autism spectrum conditions by improving the provision of relevant services by local authorities, NHS bodies and NHS foundation trusts.

**The first autism strategy, 'Fulfilling and Rewarding Lives'** was produced in 2010 and sets a clear framework for all mainstream services across the public sector to work together for adults with autism. It sets out seven quality outcome measures against which local areas in England can test how well they are meeting the aims of the Autism Strategy.

To help local areas work towards these outcomes, the document also sets out three key ambitions:

1. Local Authorities and partners know how many adults with autism live in the area.
2. A clear and trusted diagnostic pathway is available locally.
3. Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism.

**This was updated in 2014 and published as 'Think Autism'**, and from this, fifteen priority Challenges for Action were identified by people with autism, carers, professionals and others who work with people with autism.

There are duties on local authorities and NHS bodies to act under the statutory guidance produced by the Government to accompany each strategy.

**Transforming Care Partnership Plan** - The Calderdale, Kirklees, Wakefield and Barnsley (CKWB) Transforming Care Partnership are working on a plan to improve services for people with a learning disability and/or ASC in our area.

## 6. Local Autism Self-Assessment 2018

**The Public Health England Autism Strategy Self-Assessment** is intended to support local authorities to review progress in implementing the Government's Autism strategy 'Think Autism'. It covers areas including planning, training, diagnosis, care and support, housing, employment, the criminal justice system, and local innovations.

The latest submission from Calderdale covering 2017/18 is the main source of data letting us to compare Calderdale's performance with that in other areas.

## 7. The local population... facts and figures

There is limited local data on the numbers of adults with ASC without a learning disability (LD) in Calderdale. This lack of local data is not unique to Calderdale.

- Calderdale has a population of 210,082 (LA Health Profile 2018), including 168,814 adults (86,631 females, 82,183 males)
- Based on current national prevalence rates it is assumed that 1.1% of the population would have ASC, suggesting that 1857 adults living in Calderdale have ASC. (This estimate is derived from the 1.1% prevalence rate applied to the 2011 UK census figures.)
- It is predicted that 44%-52% of adults with ASC would have a LD so between 817 and 965 adults with ASC in Calderdale would also have a LD.
- Therefore 48%-56% of adults with ASC would not have a LD, so between 891 and 1,039 adults with ASC in Calderdale would not have a learning disability, between 0.5% and 0.6% of the adult population in Calderdale.

## 8. Why is getting diagnosis important for adults?

Access to a diagnosis of ASC is a major issue in a context where diagnosis or a label of some kind is essential to access services, and assessment for personalisation appears unlikely to take place without it.

- It may facilitate access to benefits, specialist services and support, or adapted mainstream services.
- Especially for those diagnosed in later life, it can be a relief and provide an explanation for challenges and difficulties they have faced, as well as providing a framework for understanding triggers which can help inform adjustments to make every day living more comfortable.
- Lack of diagnosis can contribute to a range of conditions including anxiety, depression and prolonged stress due to lack of explanation of symptoms, and behaviour not being understood by others.
- New initiatives due to be introduced in the next few years will make the recording of an ASC diagnosis in an adult's medical records even more significant; digital flagging in medical records of the needs of people with ASC is going to be introduced, including information about reasonable adjustments that can be used to help them; and annual health checks for adults with ASC are also expected to be introduced.

## 9. Ongoing discussions with Calderdale CCG in 2019

As HWC has continued to hear from adults with ASC, and those seeking a diagnosis, we have been involved in discussions with Calderdale CCG, and representatives from the Calderdale Autism Strategy Group.

The aim of the discussions has been to get a better understanding of the issues that people are having, to find out more about the barriers they are facing, and to explore ways that the current situation for adults with ASC in Calderdale could be improved.

Key themes from those discussions have been:

- The South West Yorkshire Partnership Foundation Trust (SWYFT) contract – we were told this is usually rolled over year-on-year
- The ASC referral, triage, and assessment process
- The low number of adults being diagnosed with ASC in Calderdale
- Post diagnostic support for adults receiving an ASC diagnosis
- The lack of support for adults who do not receive an ASC diagnosis
- ASC diagnoses made by other services not being accepted
- Difficulties accessing a second opinion
- Lack of patient choice in accessing services
- Lack of mental health support for adults with an ASC diagnosis

Through correspondence with the Adults with Autism Service (AAS), which provides the ASC diagnostic pathway for adults in Calderdale, we have had answers to some of the questions we have asked, although not all have been fully answered.

For example, when we asked why Calderdale has such a low diagnosis rate for ASC in adults, with only 2 diagnoses made in 2017/18, and 4 made in 2018/19, the AAS response was:

- *'The SWYPFT Service is not thought to be different from other NHS Services using a similar pathway.'*
- *'Diagnostic rates of other Services may change as expertise and consistency in the diagnosis of Autism becomes more established in response to ongoing regional work on Integrated Care Systems.'*
- *'It is of concern that the referrals put forward in Calderdale are not for people who have Autism.'*

We feel this response does not properly address the issue, and believe it needs further scrutiny.

We also had concerns about the way patient feedback and demographic data was being collected, and while we are happy to see that this is being improved there is still further work to do.

## 10. Addressing the key themes

### 10.1. The ASC referral, triage, and assessment process

**Prior to 2015:** Adults seeking an ASC assessment were referred by their GP through an Individual Funding Request to the Sheffield Adult Autism and Neurodevelopmental Service (SAANS).

**In 2015:** The Adults with Autism Service (AAS) based at Manygates in Wakefield, was commissioned to provide an adult ASC diagnostic service, on a case by case basis via GP referral through an Individual Funding Request process.

**Then in 2018, funding was provided to commission an adult ASC Assessment and Diagnostic Service.**

Dr Steven Cleasby, the Chair of the CCG's Governing Body, stated:

*'With regards to autism in adults, the CCG has invested £60,000 of recurrent funding in commissioning a new assessment and diagnosis service from SWYFT, offering initial assessment and two follow-up appointments. This new approach started in April this year. We have also provided £40,000 of non-recurrent funding to reduce the waiting list which had built up before the service was available...'* (Calderdale CCG Freedom of Information Request Disclosure Log: Services for adults with autism (1819036))

**Since April 2018 the commissioned diagnostic pathway has been in place with AAS:**

- Referrals are accepted from Consultants, GPs, or other trust services, and social workers for the Social Care Pathway.
- A monthly local triage panel reviews the referrals to check if enough information has been provided to make a decision to either accept or decline the referral.
- If the referral is accepted, an initial screening appointment is made to meet with the person to determine whether they show any indicators of ASC.
- If they do, then further assessment appointments are needed to complete the full diagnostic assessment.
- The outcome would be discussed and an assessment report sent to the person who submitted the referral, to the patient's GP, and to the patient if they wish.
- Patients with a diagnosis of ASC are then offered up to 2 more appointments to discuss the implications of the diagnosis and what support may be helpful.

At the moment access to an ASC assessment is totally dependent on GP’s input, their knowledge of the patient, and their understanding of autism and how it may present, which may be limited. The patient, who is the expert in their condition, does not get the opportunity to input into the form, in fact if they do that it can be a reason for the triage panel refusing to assess it.

Some areas, including the Leeds Autism Diagnostic Service (LADS) allow people to self-refer, which gives them the opportunity to fully explain why they are seeking an autism assessment, and to document in detail any difficulties they have had as a child or an adult which lead them to believe that they may be on the autistic spectrum. LADS recognised that having to be referred through GPs or healthcare professionals could be a barrier to accessing their service, so they decided to provide the option to self-refer.

Feedback from AAS: *‘Consideration of referrals by Triage Panels has identified the issue that poor clinical referrals can for some people restrict or delay access to the diagnostic assessment process. In response to this, the Service is in the process of further developing the Autism Referral Form to include an optional section for completion by the person seeking a diagnostic assessment to ensure the ‘voice’ of the service user is considered alongside the clinical opinion of the referrer at the earliest possible opportunity.’*

**Our Recommendations:**

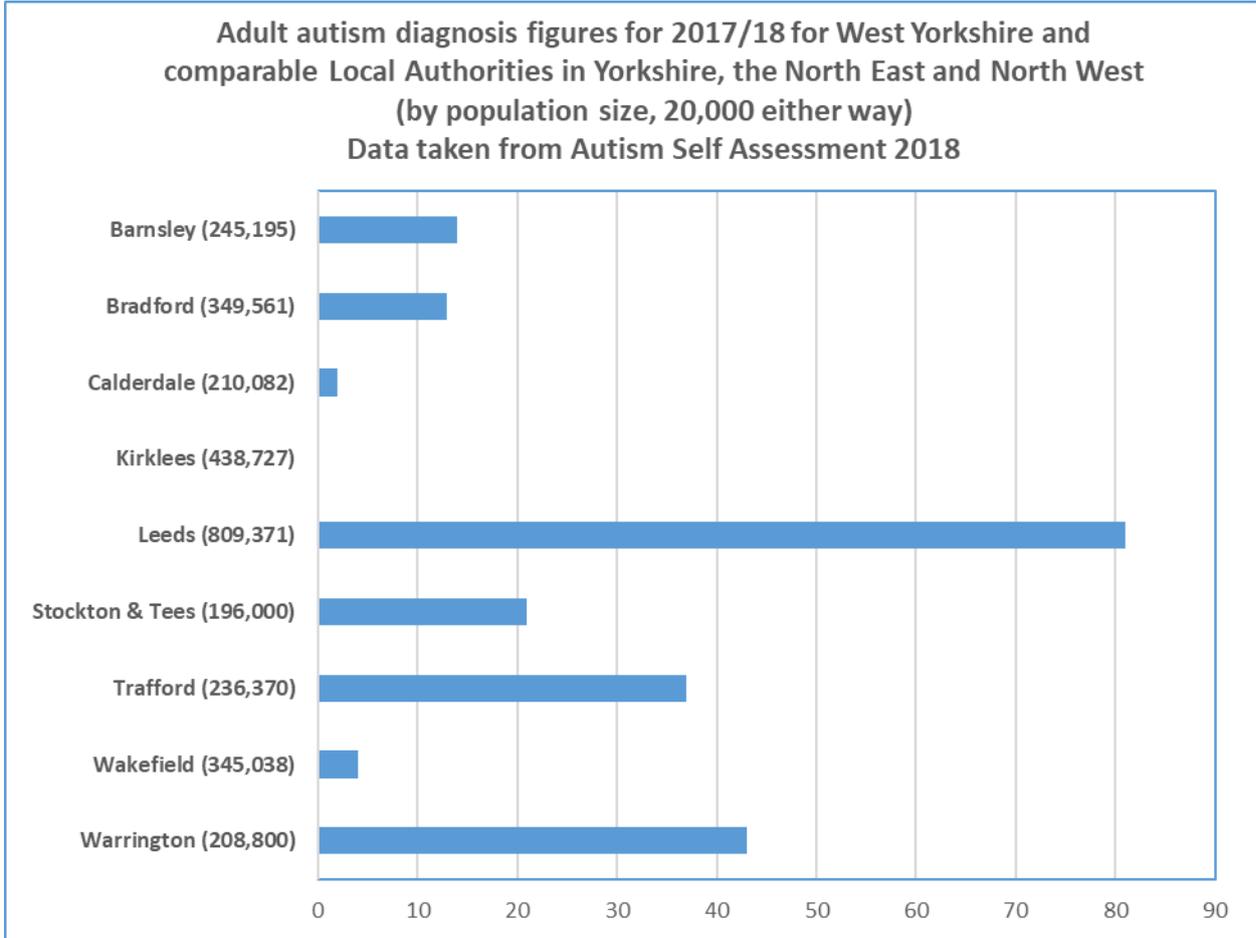
<p><b>ASC Referral Process</b></p>	<ul style="list-style-type: none"> <li>• Allow self-referrals</li> <li>• Increase the opportunity for patient input into the referral form</li> <li>• Training for GPs in completing ASC referral forms</li> <li>• Alternatively return to a model where referrals are accepted that have the support from a GP and/or Mental Health Practitioner and a face to face initial assessment is offered to all referrals.</li> </ul>
<p><b>ASC Referral Triage</b></p>	<ul style="list-style-type: none"> <li>• Provide the option for face to face triage assessment for all referrals</li> <li>• Training for GPs in recognising how ASC traits can present in adults</li> <li>• Support for individuals whilst they are awaiting an ASC assessment</li> </ul>
<p><b>ASC Assessment Process</b></p>	<ul style="list-style-type: none"> <li>• Consider whether using a broader range of formal assessment tools, including DISCO, would enhance the assessment process offering a more personalised service</li> </ul>

**10.2. Low numbers of adults being diagnosed with ASC in Calderdale**

**Based on the data in the Autism Self-Assessment 2018, in 2017/18, only 2 adults received a diagnosis of ASC.** Out of the 55 adults in Calderdale who were referred for an ASC assessment, only 2 received a positive diagnosis, a diagnosis rate of 3.6%.

**The difference in diagnostic rates across England.** This is highlighted by the 120 responses in the Autism Self-Assessment 2018 which included the number of adults diagnosed with ASC in 2017/18. The responses range from 0 to 432, and while the areas have widely differing population sizes, Calderdale with only 2 diagnoses in that year is within the lowest 1%.

The table below allows you to compare the number of diagnoses in Calderdale, other local authorities in West Yorkshire, and other local authorities comparable by size.



**The total number of adult ASSC diagnoses in 2017/18 across all 120 areas which responded was 7,836:** this would give an average of 65.3 diagnoses per area if they were all of a similar population size.

**In Calderdale in 2018/19 only 4 adults received a diagnosis of ASC.**

No of referrals considered by Triage Panel	<b>136</b> (84 male, 52 female)
No of referrals accepted by Triage Panel	<b>34</b> (23 male, 11 female)
No of referrals receiving a full diagnosis of ASC	<b>4</b> (2 male, 2 female)

We are grateful to the AAS for providing us with 2018/19 data for adult ASC diagnoses. This data shows that 34 of the 136 referrals for an ASC assessment were accepted by the Triage Panel, and of the 34 adults who received a full diagnostic assessment, only 4 received a diagnosis of ASC, a diagnosis rate of 12%.

**Comparative data for Kirklees and Wakefield has also been provided:**

Locality	Diagnostic Rate	Number assessed
Calderdale	12%	4 out of 33 people who required a <u>full diagnostic assessment</u> met the criteria for a diagnosis of ASC
Kirklees	35%	6 out of 17 of people who required a <u>full diagnostic assessment</u> met the criteria for a diagnosis of ASC
Wakefield	27%	4 out of 15 people who required a <u>full diagnostic assessment</u> met the criteria for a diagnosis of ASC

The low diagnosis rate in Calderdale for adults with ASC has been of concern for some time: *‘There is an ongoing concern regarding the SWYFT diagnostic service as the diagnostic rates are very low. This leads to frustration and requests for a second opinion from the Sheffield diagnostic service. Calderdale CCG who fund the diagnostic service are aware of these concerns...’* (Report to Adult Scrutiny panel: 28/03/17)

**AAS responded:** *‘It is expected the diagnostic rate in Calderdale will increase in 2019/20 as a result of referral triage and improved quality of referral information.’*

**Our Recommendations:**

<b>Service Data</b>	<ul style="list-style-type: none"> <li>• More local data is needed about rates of ASC diagnosis, ASC referral rates, and the referral-to-assessment times</li> <li>• Where appropriate, include age, gender, ethnicity, geographical location and commissioning area</li> <li>• The reason for the very low rate of ASC diagnosis in Calderdale needs to be explored and explained</li> </ul>
<b>Patient feedback</b>	<ul style="list-style-type: none"> <li>• Involve experts by experience in the monitoring and development of services</li> </ul>

### 10.3. Post diagnostic support for adults receiving an ASC diagnosis

There is no post diagnostic clinical treatment commissioned for adults receiving a diagnosis of ASC in Calderdale if they do not have a learning disability.

In Barnsley and Wakefield, AAS offer a health intervention pathway which may include a variety of different kinds of support from the multi-disciplinary team. Using a person-centred care plan support can include social skills training, psychological intervention, occupational therapy and organisational skills, access to health care and speech and language input.

In Kirklees there is a Specialist Social Worker who can offer a Social Care Pathway, including such things as the development of care packages and support to access to educational, social care and employment opportunities.

#### Our Recommendations:

<b>Post diagnostic support</b>	<ul style="list-style-type: none"> <li>• Provide a range of post diagnostic support for adults with ASC in Calderdale</li> <li>• Make it easier for adults with ASC to access post diagnostic support out of area if it is not available in Calderdale</li> <li>• Clarify the use of individual funding requests (IFRs) for funding counselling for adults with ASC</li> </ul>
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### 10.4. The lack of support for adults not receiving an ASC diagnosis

Following the outcome of the Diagnostic Assessment, AAS offers post-diagnostic support in the form of a specific post-diagnostic pack for those who do not receive a diagnosis.

*AAS responded: 'On completion of the diagnostic assessment process clinicians endeavour to signpost people to appropriate Services for further assessment, treatment and support...We acknowledge the potential impact for people not getting a diagnosis and clinicians working in the SWYPFT diagnostic pathway have undertaken training in the skill of 'Breaking Bad News' to people in the healthcare environment.'*

#### Our Recommendations:

<b>Post diagnostic support</b>	<ul style="list-style-type: none"> <li>• Enhance the support given to people who do not receive an ASC diagnosis so that they can access appropriate services and care.</li> </ul>
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### **10.5. ASC diagnoses made by other services not being accepted**

Even though Calderdale does not commission any post diagnostic services for adults with ASC, if somebody who already has a diagnosis, possibly before moving to Calderdale, is trying to access support via an Individual Funding Request, their diagnosis may well be called into question even though it was made by a qualified clinical specialist.

A number of people who have received a diagnosis of ASC in a different area, or by a service other than AAS, have had their diagnosis questioned when they have tried to seek support, and in some cases they have had their diagnosis of ASC 'undiagnosed'. This has happened to people with both private and NHS ASC diagnoses.

One client reported moving to Calderdale recently, but despite having a diagnosis of ASC from a neuropsychologist following extensive tests, she was told that she must be re-referred to AAS before she can seek any support, and that there is an 18 month waiting list for this.

#### **Our Recommendations:**

<b>ASC diagnosis</b>	<ul style="list-style-type: none"> <li>• Clarify the position regarding ASC diagnoses made by services other than AAS</li> </ul>
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### **10.6. Difficulties accessing a second opinion**

If the individual is deemed not to have ASC, either at the triage or the assessment stage, they have great difficulty accessing a second opinion. There is a particular concern that people who have lived with the condition undiagnosed for years and have learnt to mask it are not getting a diagnosis.

#### **Our Recommendations:**

<b>Getting a second opinion</b>	<ul style="list-style-type: none"> <li>• Clarify the use of individual funding requests (IFRs) to fund second opinions.</li> <li>• Clarify whether Patient Choice in mental health applies to ASC diagnostic assessments</li> </ul>
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### **10.7. Lack of Patient Choice in accessing services**

Healthwatch and many other professionals and individuals believe that Patient Choice in mental health should apply to ASC diagnostic assessments.

The CCG states that it is waiting for guidance on this from NHS England, but HWC is aware of an individual who recently obtained NHS funding for an alternative assessment at private provider, Axia, following a complaint to the CCG after being turned down for a local ASC assessment. Axia diagnosed the individual with ASC. Axia ASD Ltd, who provide a specialist neurodevelopmental assessment service, are well respected and have contracts with several CCGs and CAMHS.

There also needs to be clear guidance about the use of Individual Funding Requests (IFRs) for accessing a second opinion, or for funding specific counselling for adults with ASC.

**Our Recommendations:**

<b>Patient Choice</b>	<ul style="list-style-type: none"> <li>• Clarify the use of individual funding requests (IFRs) to fund ASC specific counselling</li> <li>• Clarify whether patient choice in mental health applies to ASC diagnostic assessments</li> </ul>
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**10.8. Lack of mental health support for adults with ASC diagnoses**

While autism is not a mental illness, rates of mental ill health and suicide are exceptionally high in the autistic population. There is an urgent need for practitioners to understand and deal with the barriers autistic people face in accessing mental health support.

We have found that access to generic mental health services is very restricted for adults with ASC and we have heard reports of difficulties in obtaining mental health support (both crisis and ongoing) from many people with this condition.

One client, who has a range of difficulties including ASC and obsessive-compulsive disorder (OCD) explained that it had been very difficult to get any kind of mental health support. This client tried to access cognitive behavioural therapy but was told that because she had ASC she would not benefit from it, and she was not referred for any other support.

Another client with ASC reported that she received a support worker via her local mental health service. The woman had begun to connect her ASC with her anxiety and depression, but her mental health support worker was not trained in ASC and was uninterested in the connection between the ASC and anxiety. As a result, the CBT offered did not work for the client and she was discharged without support.

Another client suffers from depression and low self-esteem but cannot access mental health support because she has ASC.

The CCG states that it *‘expects the mental health services it commissions to make reasonable adjustments for any particular needs that individuals may have, including autism. If an individual with autism needs specialist mental health support, they can be referred by their GP or another clinician through the CCG’s Individual Funding Request process.’* (Calderdale CCG Freedom of Information Request Disclosure Log: Services for adults with autism (1819036))

Calderdale has generic mental health services suitable for people with primary mental health needs, however they do not have enough knowledge or awareness of ASC to adapt support for the people who approach them. Some individuals who have approach HWC have been told that ASC is their primary health need, and as such, they cannot access mental health support as SWYT are not commissioned to deliver ASC support. People come to HWC for support in trying to access services for ASC, as well as for help in accessing specific therapies such as Dialectical Behaviour Therapy (DBT), but these services are not commissioned routinely, therefore if people want to access them they have to submit an Individual Funding Request (IFR) to the local CCG.

**NICE Guidance:**

- for adults with ASC and a mental health condition, the NICE guidelines for treating the mental health condition should be followed, with modifications to make them more effective and accessible to people with ASC.
- where there are gaps in availability of psychosocial support, CCGs may need to work together with the local authority to commission additional interventions... Some individually tailored psychosocial support may be needed to help people with ASC to develop their social, communication and life skills’
- suggests that investment in services for people with ASC can lead to reductions in GP appointments, fewer emergency admissions and less use of mental health crisis services.

**Our Recommendations:**

<b>Mental Health Services</b>	<ul style="list-style-type: none"> <li>• Adapt mental health therapies to make them suitable for adults with ASC.</li> <li>• Increase understanding of autism and co-morbid conditions (mental health)</li> <li>• More choice in mental health services</li> </ul>
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## 11. Summary of Recommendations

Item	Recommendation	Responsibility
<b>ASC Referral Process</b>	<ul style="list-style-type: none"> <li>• Consider allowing self-referrals</li> <li>• Increase the opportunity for patient input into the referral form</li> <li>• Training for GPs in completing ASC referral forms</li> <li>• Alternatively return to a model where referrals are accepted that have the support from a GP and/or Mental Health Practitioner and a face to face initial assessment is offered to all referrals.</li> </ul>	
<b>ASC Referral Triage</b>	<ul style="list-style-type: none"> <li>• Provide the option for face to face triage assessment for all referrals</li> <li>• Training for GPs in recognising how ASC traits can present in adults</li> <li>• Support for individuals whilst they are awaiting an ASC assessment</li> </ul>	
<b>ASC Assessment Process</b>	<p>Consider whether using a broader range of formal assessment tools, including DISCO, would enhance the assessment process offering a more personalised service</p>	
<b>Service Data</b>	<ul style="list-style-type: none"> <li>• More local data is needed about rates of ASC diagnosis, ASC referral rates, and the referral-to-assessment times</li> <li>• Where appropriate, include age, gender, ethnicity, geographical location and commissioning area</li> <li>• The reason for the very low rate of ASC diagnosis in Calderdale needs to be explored and explained</li> </ul>	
<b>Patient feedback</b>	<ul style="list-style-type: none"> <li>• Involve experts by experience in the monitoring and development of services</li> <li>• Consider including adults with ASC in an Autism Reference Group</li> </ul>	

<p><b>Post diagnostic support</b></p>	<ul style="list-style-type: none"> <li>• Provide a range of post diagnostic support for adults with ASC in Calderdale</li> <li>• Make it easier for adults with ASC to access post diagnostic support out of area if it is not available in Calderdale</li> <li>• Clarify the use of individual funding requests (IFRs) for funding counselling for adults with ASC</li> <li>• Enhance the support given to people who do not receive an ASC diagnosis so that they can access appropriate services and care.</li> </ul>	
<p><b>ASC diagnosis</b></p>	<ul style="list-style-type: none"> <li>• Clarify the position regarding ASC diagnoses made by services other than AAS</li> </ul>	
<p><b>Getting a second opinion</b></p>	<ul style="list-style-type: none"> <li>• Clarify the use of individual funding requests (IFRs) to fund second opinions.</li> <li>• Clarify whether patient choice in mental health applies to ASC diagnostic assessments</li> </ul>	
<p><b>Patient Choice</b></p>	<ul style="list-style-type: none"> <li>• Clarify the use of individual funding requests (IFRs) to fund ASC specific counselling</li> <li>• Clarify whether patient choice in mental health applies to ASC diagnostic assessments</li> </ul>	
<p><b>Mental Health Services</b></p>	<ul style="list-style-type: none"> <li>• Adapt mental health therapies to make them suitable for adults with ASC.</li> <li>• Increase understanding of autism and co-morbid conditions (mental health)</li> <li>• More choice in mental health services</li> </ul>	

## 12. Glossary of terms

- **(ADHD) Attention Deficit Hyperactivity Disorder:** is a behavioural disorder that includes symptoms such as inattentiveness, hyperactivity and impulsiveness
- **(ADOS) The Autism Diagnostic Observation Schedule:** is a semi structured assessment for communication, social interaction and play for individuals who are suspected of having autism. This consists of standardised activities that allow behaviour to be observed.
- **(ASC) Autism Spectrum Condition:** is a lifelong developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around.
- **(AAS) Adults with Autism Service:** This service provides diagnostic assessment and/or specialist interventions for people who are 18 years+ and do not have an intellectual disability across Barnsley, Calderdale, Kirklees and Wakefield.
- **(CAMHS) Children and Adolescence Mental Health Service:** this is a specialist service offering assessment and treatment for children and young people who have emotional, behavioural or mental health difficulties.
- **(CCG) Clinical Commissioning Group:** the organisation that commissions (pay for) local NHS services, including mental health services.
- **(Calderdale CCG) Calderdale Clinical Commissioning Group:** the organisation that commissions (pays for) local NHS services in Calderdale. They commission the ASC diagnostic pathway.
- **(GP) General Practitioner:** A doctor based in the community within a GP practice that treats patients and refers them on to additional services.
- **(HWC) Healthwatch Calderdale:** is the independent consumer champion for anyone in Calderdale who uses health and social care services. We use the views and experiences of local people as evidence to influence improvements in service provision.
- **(JSNA) Joint Strategic Needs Assessment:** is a document that looks at the current and future health and care needs of a local population to inform local planning and commissioning of services.
- **(NAS) National Autistic Society:** is a national charity supporting autistic people and their families, their aim is to improve the lives of autistic people across the UK.
- **(NHSE) NHS England:** oversees the budget, planning, delivery and day-to-day operation of the commissioning (funding) side of the NHS.
- **(NICE) The National Institute for Health and Care Excellence:** provides national, evidence-based guidance and advice to improve health and social care.
- **(SWYFT) South West Yorkshire NHS Foundation Trust:** The organisation that commissions mental health, community, learning disability and wellbeing services, including the AAS, across Barnsley, Calderdale, Kirklees and Wakefield.

## 13. Useful resources – links to online information

- [The Autism Act](#)
- [Rewarding and fulfilling lives](#)
- [Think Autism](#)
- [Autism Aware eBook](#) for GPs and hospitals, etc.
- [Autism Awareness Animations](#) developed by a member of the Halifax Autism Hub: (Menu in top-right corner, then 'Projects')
- [Autistica Briefings](#)
- [Autistica Report – 'Personal tragedies, public crisis'](#)
- [DoH: Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#)
- [Healthwatch Calderdale report: Adults' experiences of Autism Services in Calderdale and Kirklees](#)
- [House of Commons: Mental Health and Suicide within the Autism Community](#)
- [London School of Economics National Autism Project report- THE AUTISM DIVIDEND: Reaping the rewards of better investment](#)
- [NAS Good Practice Guides](#)
- [NAS report – The Autism Act: 10 Years on - A report from the All Party Parliamentary Group on Autism on understanding, services and support for autistic people and their families in England](#)
- [National Autistic Taskforce \(NAT\) An Independent Guide to Quality Care for Autistic People](#)
- [NHS: Other conditions that affect autistic people](#)
- [NHSE: Choice in mental health care: Guidance on implementing patients' legal rights to choose the provider and team for their mental health care](#)
- [NICE Clinical Guidance: Autism spectrum disorder in adults: diagnosis and management](#)
- [Public Health England: Autism self-assessment framework](#)
- [Royal College of General Practitioners information and a toolkit for GPs and practice staff, as well as patients, carers and commissioners](#)

## 14. Appendices – Links and attached documents

- [Service User Information, Autism Diagnostic Pathway - Frequently Asked Questions](#)
- [Referral form for the Service for adults with autism](#)
- [Autism in Adulthood- Guidance for Referrers](#)
- [Leeds Autism Diagnostic Service self-referral form](#)
- [Calderdale CCG Freedom of Information Request Disclosure Log: Services for adults with autism \(1819036\)](#)
- **Appendix 1 - Autism Referral Form - Part 2 (Optional): To Be Completed by The Individual Seeking a Referral**
- **Appendix 2 - Service user and Carer involvement feedback - 17th July 2019, @Manygates Clinic**
- **Appendix 3 - Service for Adults with Autism Service user satisfaction questionnaire: Diagnostic pathway**
- **Appendix 4 - Service for Adults with Autism Service User satisfaction questionnaire 19/20SE12: Diagnostic Pathway and Assessment Screening results**

### Appendix 1:

**PART 2 (OPTIONAL): TO BE COMPLETED BY THE INDIVIDUAL SEEKING A REFERRAL**  
Please write anything else you would like us to know to support your referral

## Appendix 2:

Service user and Carer involvement feedback meeting 17<sup>th</sup> July 2019, @Manygates Clinic

**Present** - Service User, Staff

**Discussion** - The purpose of the meeting was to look at the Diagnostic process of the Autism Pathway and to discuss what was good and what could be improved. Introductions were made and that all opinions were valid.

**Comments:**

- Experiences were that once in the system things progressed fairly quickly but it was a long wait to get there
- Referral process and getting through the first appointment not always informed of where the service user was
- Going to the home environment was a good idea- could be used more for some people
- Listen to the carer as well as the individual
- Never felt rushed in process
- Send Non-confidential documents by e-mail for some who would prefer this
- Put info in letters about some receptions not being manned.
- Photos of reception areas to inform people they have come to the right place.
- Consider lighting
- More information on parking please
- Rooms were generally ok
- Seeing the same person was good, students were fine
- No comments on the readability of information just overwhelming when given in one go. May be individual preferences though
- Appointments spaced out well – should be a couple of weeks between each not 6 weeks
- Would not want the whole assessment in one day as would be too stressful.
- AFG said process for him was quicker than expected
- Diagnostic report too clinical- too much clinical terminology did not understand. More focus on what made the clinician decide why he was autistic (more focus on the formulation basically)
- Perhaps a service user version of the report
- Explanation of the ADOS scores would be useful- cut off points- put in conversion table from the module booklet
- Confident of the knowledge of the team members seen
- On point of referral would like more information
- Update on progress of referral every 6 months.
- Statement about- What happens if I don't agree with the outcome. Perhaps this is too early to mention at this point. - Could it be provided later- At time of decision?

### Appendix 3:

#### Service for Adults with Autism Service user satisfaction questionnaire: Diagnostic pathway

We would like to find out how satisfied you are with our service. Please tick in the box to indicate how much you agree or disagree with these statements

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
I was able to contact the team if I needed to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The team treated me with respect and dignity throughout the process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was given enough time to process information and discuss my difficulties and needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was asked about my preferred communication method	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am happy with the location of my appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The room was comfortable and quiet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I received enough information about the team when I was first contacted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The pre appointment information pack explained the assessment process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The pre appointment information pack was easy to read and understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The team involved were approachable, accessible and I found it easy to talk to them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was able to ask questions and the team were proactive in answering these	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The outcome of the assessment was clearly explained	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I was given enough time to discuss the outcome of the assessment	<input type="checkbox"/>				
I am happy with the support I received from the team	<input type="checkbox"/>				
I was asked if I wanted my family, partner or carer to be involved in the process?	<input type="checkbox"/>				
I was confident that the team had a good understanding of autism?	<input type="checkbox"/>				

**What do you think is good about the service?**

**What do you think we can improve on?**

**Which locality do you live in?**

Wakefield  
 Kirklees  
 Calderdale  
 Barnsley

**I give my permission for my feedback to be used in any publicity by the team**  
 Yes      No      (please circle)

**Thank you for taking the time to complete this questionnaire. Please return in the envelope provided.**

## Appendix 4:

### Service for Adults with Autism (SAA) Service User satisfaction questionnaire 19/20SE12: Diagnostic Pathway and Assessment Screening results.

See below an example of the questions and feedback, with the summary comments on the following page. A copy of the full questionnaire results can be provided if required.



**South West  
Yorkshire Partnership**  
NHS Foundation Trust




## Service for Adults with Autism Service User satisfaction questionnaire 19/20SE12

### Diagnostic Pathway and Assessment Screening results

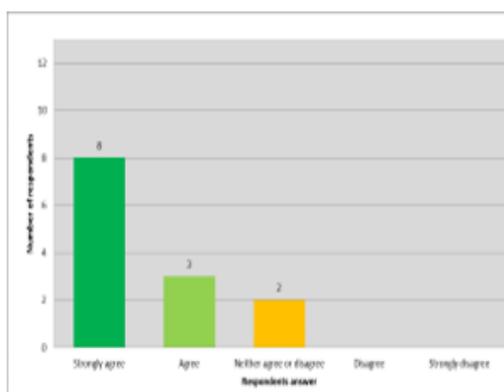
December 18 – June 2019



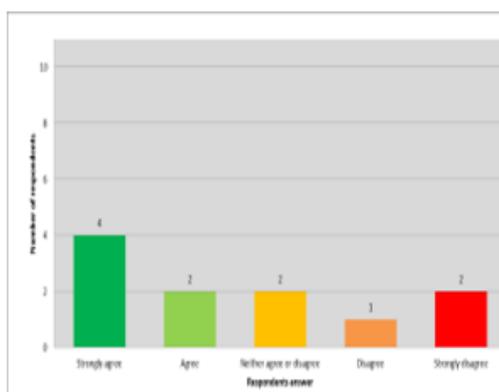



Q1. I was able to contact the team if needed to

Diagnostic pathway		
Answer Choices	Responses	%
Strongly agree	8	62%
Agree	3	23%
Neither agree or disagree	2	15%
Disagree		0%
Strongly disagree		0%
Total:	13	



Screening assessment		
Answer Choices	Responses	%
Strongly agree	4	36%
Agree	2	18%
Neither agree or disagree	2	18%
Disagree	1	9%
Strongly disagree	2	18%
Total:	11	



**In response to service user feedback we have updated the format of this report to show:**

- The feedback received from people who have had a full diagnostic assessment completed (Diagnostic Pathway)
- The feedback received from people who have had an initial screening assessment completed and did not meet the criteria for further diagnostic assessment of Autism (Screening Assessment)

**What you think is good about the Service...**

- Clinicians who completed assessments described as “friendly”, “intuitive, polite and understanding regarding the subject of autism”, “professional and an extreme pleasure to talk with”
- “Staff have zero room for improvement, the paperwork presents no issues and facilities are excellent”
- There are shorter waiting times to access the Service in some Trust localities “I received relatively early the appointment (without long waiting, like more than 12 months, or so). In this regard I was lucky”

**What you think we can improve on...**

- Making reasonable adjustments at clinic venues “the venue was too noisy and too many people around me to feel comfortable”, “I do not like bright lights and was more focused on the brightness of the light in the room hurting my eyes and giving me headache, “I think the seating could be better and more gentle in approach”.
- Equality in waiting times across Trust localities “The waiting times for an autism assessment is horrendous as it can take years in some instances before you are seen by a professional assessor but I appreciate also that a lot of people require this service”
- Avoid using language that not everyone understands “He kept on talking about politics scenarios which I told him I did not understand and had to repeat them constantly”.
- Letting people know what qualifications and training clinicians who complete the assessments have “More healthcare professionals with autism spectrum awareness needed. Especially in cases of aged autistic females”, “I think that a professional with understanding of Autistic spectrum would be of great help”.

**What have we done in response to your feedback...**

- We have amended the format of this report to show the feedback of those people who have had an initial screening assessment and those who have completed the full diagnostic assessment.
- Our Frequently Asked Questions Fact Sheet tells people what professionals will carry out the assessment and that all members of the Multidisciplinary Team (MDT) have specialist knowledge and training in Autism.
- We have dealt promptly with individual informal and formal complaints with support from the Trust Customer Service Team when required.
- We will update the feedback questionnaires to reflect the locality the person was seen. This will help us to address any issues with regard the clinical bases we are using across the Trust localities.